

Gender Atypical Organisation in Children and Adolescents: Ethico-legal Issues and a Proposal for New Guidelines

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Introduction

Case histories

1. Jan Morris

I was three or perhaps four years old when I realized that I had been born into the wrong body, and should really be a girl. I remember the moment well, and it is the earliest memory of my life.

I was sitting beneath my mother's piano, and her music was falling around me like cataracts, enclosing me as in a cave. The round stumpy legs of the piano were like three black stalactites, and the sound-box was a high dark vault above my head [...] On the fact of things it was pure nonsense. I seemed to most people a very straightforward child, enjoying a happy childhood. I was loved and I was loving, brought up kindly and sensibly, spoiled to a comfortable degree [...] by every standard of logic I was patently a boy. I was named James Humphry Morris, male child. I had a boy's body. I wore a boy's clothes [...] (Morris, 1974, pp. 1–2)

2. James

James was referred to the Gender Identity Development Service at the age of 8 years. At the assessment interviews, he said that since the age of 4 or 5 he had very much wished he were a girl. He had been secretly dressing up in his mother's clothes. He liked to play with dolls and cuddly toys and fantasised that he was a mother feeding them. He played weddings and liked to be in the role of the bride. At school he wanted to play with girls and avoided rough-and-tumble play or other activities with boys (Di Ceglie, 2000, p. 460)

3. Mark

Mark, aged 16 years, presented a gender identity disorder of a transsexual type. He hated his male body intensely. Socially isolated and in despair, he had attempted suicide. Since the age of 3 or 4 years he had felt that he was a girl [...]

4. Jerry

(My mother) went to the trouble of finding two identical dresses—one for me and one for my sister. My sister loved hers. I didn't. Mother put the dress on me, I took it off. My mother put it one me again and I took it off. She tried again and again, and I took it off again—only this time I cut it up with scissors. (Kotula, 2002, pp. 92–94)

These are four stories of children with atypical gender development. Different nomenclature applies to the experience of atypical gender development. The DSM-IV utilises the term Gender Identity Disorder (GID) (DSM-IV-TR, 2000). In this paper, I will use the term Atypical Gender Identity Organisation (AGIO), first suggested by Domenico Di Ceglie (Di Ceglie, 1995, chapter 2).

There are no agreed international guidelines on the treatment of children and adolescents with AGIO. Different countries adopt different approaches. This paper offers a contribution to the establishment of guidelines that are coherent with ethical and legal principles accepted in the UK and worldwide. New guidelines for treatment of children and adolescents with AGIO are needed for at least four reasons:

1. to remove the inconsistencies between the approaches recommended by health care professionals across different countries and also by different associations and colleges in the UK;
2. to remove the inconsistencies between the way minors with AGIO are treated, as compared with children suffering from other conditions;
3. to ensure that treatment of minors with AGIO is not only clinically, but also ethically appropriate;
4. to allow health care professionals to safely exercise the clinical judgment to undertake the course of action which is in the child's best interests.

Focus will be on the entitlement to receive treatment. For reasons of space and consistency, this paper will not consider the issue of whether treatment should be publicly funded. The defence of the entitlement to be treated and definition of clear guidelines is, however, preliminary to any further discussion of how treatment should be funded.

In the first part of the paper, I will summarise what AGIO is and how it manifests. This should help non-specialist audiences to become familiar with the problem.

In the second part, I will focus on ethico-legal issues surrounding treatment of children and adolescents with AGIO. I will outline available interventions for AGIO, their risks and benefits, and I will argue that it is possible, either for an adult or for a competent child, to give valid informed consent to treatment for AGIO. This implies that AGIO (whether or not it should be considered as a mental illness) does not *ipso facto* entail incompetence to decide about treatment.

Guidelines currently in use in the UK risk being incongruent with English legislation and with the ethical principles that such legislation incorporates. I will make suggestions as to how guidelines should be framed, in order to gain consistency with both legal and ethical principles widely accepted in healthcare ethics and law.

2 *What AGIO Is*

AGIO is described as a "rare condition in which individuals experience their 'gender identity' as being incongruent with their *phenotype* (the external sexual characteristics of the body). The personal experience of this discomfort is termed *gender dysphoria*. In its profound and persistent form, it is known as *transsexualism*" (GIRES *et al.*, 2006). Transsexualism is not the inevitable outcome of AGIO. In some cases, the person with atypical gender development—usually manifested in atypical gender role behaviour—will become homosexual, transvestite or heterosexual. Whereas some sources report that only a small minority of children with AGIO will become transsexual (the majority developing homosexual orientation or heterosexual orientation without transvestitism or transsexualism) (Royal College of Psychiatrists, 2003, p. 5), others contend that the earlier the phenomenon arises, the more rigidly structured it is likely to become during growth (Di Ceglie, 2000, p. 462). Those experiencing it in adolescence, instead, almost invariably go on to experience it in adulthood (Wren, 2000).

3 *When and How AGIO Manifests Itself*

AGIO may manifest at different stages of a person's life. In children, it may arise in pre-pubertal age, becoming more acute with the onset of puberty. Di Ceglie describes the profound discomfort experienced by children and adolescents as follows: "Their interests, their play, their fantasies, their way of moving or talking, their way of relating to friends, or their way of seeing themselves do not fit the body that they have and the way that other people perceive them as a consequence of their bodily appearance. One might say that their psyche lives in a foreign body [...] The child feels driven to live in this confusing and bewildering condition" (Di Ceglie, 1998, p. 186).

In addition, since the child is often aware of not meeting the expectations of others, s/he may experience strong feelings of guilt (Giordano, 2003).

During adolescence, the unease becomes more distressing. As puberty progresses, trans boys may develop breasts, may start to menstruate and sometimes become frustrated by their small stature. Trans girls' voices may deepen, they may grow beards and prominent Adam's apples, experience erections and become taller than most other women. The uncertainty over the sense of self, and the

secrecy and isolation that often accompany the adolescent through atypical gender development, may lead the adolescent to experience psychological disintegration. Children and adolescents with AGIO are at high risk of suicide (Di Ceglie, 1998, p. 194) (Di Ceglie *et al.*, 2002).

It should be noted that not only denigration, but also open violence is sometimes used against people, including children and adolescents, with unusual gender expressions. Clearly, violence is the extreme manifestation of psychological and social rejection of the phenomenon (Di Ceglie, 2000, p. 458). In this context, self-isolation and sense of secrecy appear an appropriate form of self-defence.

4. Epidemiology and Aetiology

The incidence and prevalence of AGIO in children and adolescents have not been established with certainty (Di Ceglie, 2000). Over the last ten years, the Portman Clinic, has seen the number of referrals rise from 15 to between 50–60 per annum (Di Ceglie, 2005).

With regard to the causes of AGIO, no single cause has been found. Whereas some experts stress the importance of psycho-familial factors (Di Ceglie *et al.*, 2002), there seems to be something impermeable and strongly embodied in one individual, which determines his or her gender identity independently of the phenotype, of the way he or she is raised, and of the traumatic experiences he or she might have had.

Observations of children treated for those intersex conditions that involve ambiguous genitalia show that gender identity is not always coherent with genital appearance. In these cases, it has been common practice to reduce the genitalia, surgically, to an unambiguous female appearance, and to raise the children as girls, and in addition, to give hormonal support consistent with this reassignment at a later stage. This is not always successful, and cases where the individual reverts to an apparently innate, indelible gender identity demonstrate that gender cannot always be moulded by upbringing and even by surgery. Research also shows that genetic, hormonal and neuro-developmental factors predispose to AGIO (GIRES *et al.*, 2006).

5. Epistemological Issues

Gender Identity Disorder was first included in the DSM-III in 1980. It is now included in the DSM-IV and in the ICD-10 (F64) (ICD-10, 1992). The ICD-10 also includes Gender Identity Disorder of Childhood (at F64.2). There is thus a formal diagnosis for atypical gender identity development.

It seems likely that AGIO is regarded as a mental illness principally for three reasons:

- One is that AGIO is invariably connected with psychological distress, both in the sufferer and in the family.
- Another is that no single somatic cause has been isolated for the condition, and therefore it is postulated that the condition must be psychological or psychiatric in nature (however, as we have seen in the previous section, it has been suggested that hormonal, neurodevelopmental, and possibly genetic factors seem to predispose to the condition).
- Finally, the gender organisation that occurs in people with AGIO is regarded as a deviation from 'normal species functioning'. The assumption is that it is normal for our species to be either a male or a female and for the gender identity to conform to our physical appearance.

One of the reasons for having a formal diagnosis is to obtain health insurance coverage and NHS treatment on an equal footing with other medical conditions. Moreover, the existence of a formal diagnosis encourages research developments, which will hopefully help to offer more effective treatments in the future (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, 2001, p. 6). However, psychiatric diagnoses always impose on the individual a stigmatising label that fails to capture the existential dimension of the person's experience.

The issue of whether AGIO is appropriately regarded as an illness, and in particular as a mental illness, is not central to this paper. In fact, people's (including children's) entitlement to receive help should not be affected by the way AGIO is classified. The central issue is whether sufferers are competent to make decisions relating to their condition and available treatment. It is accepted that people with mental illnesses can be competent to decide on matters relating to their condition, and at least *prima facie*, their right to exercise their competence should be respected (Giordano, 1999, 2001).

However, it is important to reflect on the nature of AGIO, because the way AGIO is understood or perceived by many can affect the way sufferers are treated, both in medical settings and in society at large.

With regard to the first reason for considering AGIO as a mental illness, it is true that AGIO is invariably connected with psychological distress in the individual and in the family. However, many other serious medical conditions that determine significant changes in the life of the individual have a similar resonance in the person and his/her family. An evident case is cancer. Cancer is always connected with profound distress, even depression. However, this does not make cancer a mental illness.

With regard to the second reason, namely that no single somatic cause has been identified, there are two points to make. One is that a compound of causes seems to be associated with the condition. The other is that if no single physiological cause were isolated, this could be a reason for regarding AGIO not as an illness at all, rather than as a mental illness. In a similar way, also because no single physiological cause for homosexuality has been identified, homosexuality is regarded as an existential condition, and not as an illness. The second reason listed above, thus, is not a valid reason to regard AGIO as a mental illness. It is rather a reason for not regarding AGIO as an illness at all.

The third reason listed above deserves particular attention in this context. In western societies, gender is seen as an unambiguous part of personal identity. The assumption is that normality requires congruence between gender identity and phenotype, and requires unambiguous belonging to one gender or to the other. Because of the rigid 'male or female' polarisation, ambiguity or rejection of phenotype is regarded as a deviation from normal species functioning and therefore as an illness.

In a context where only a bi-polarised structure of gender identity is accepted, the person living in an unrecognised *chiaroscuro*, a no-man's-land inhabitant, will experience an extreme sense of estrangement that may be psychologically disintegrating. It is in fact postulated that in societies where there is greater flexibility in the gender divide, atypical gender developments are less likely to be associated with co-morbidities (Connolly, 2003).

The distress that people with gender ambiguity suffer is therefore twofold: it includes, disgust with phenotype, which is inherent to the condition, and, in addition, the difficulty of accepting the incongruence with gender stereotypes. Society has gender role expectations which are congruent with phenotype; the child with AGIO has expectations that are incongruent with phenotype. The discomfort with gender role expectations is an added dimension to the disgust with phenotype.

Gender development—either 'normal' or 'abnormal'—should not be regarded merely as an intra-psychic phenomenon, but also as a social phenomenon, because it is in an important way determined by social categories and stereotypes about gender identity. Atypical gender development becomes particularly problematic within a socio-cultural context. We struggle to contemplate gender ambiguity or differences as one of the many, normal, paths open to individuals, and the psychological distress experienced by the sufferer and the family is partly due to the difficulty of accepting the reality of 'a third way'.

It is to be noted that the UK team, led by Domenico Di Ceglie, has the merit to pay utmost attention to the integration of the individual in the society. The public at large appears still widely uninformed about the matter. Specialists and patients complain that even general practitioners often lack competence to identify problems of gender identity and refer children to specialist clinics (oral communication, May 2005). Understanding AGIO as an existential condition, which becomes

particularly problematic due to social categories and stereotypes about gender identity is important in the context of framing new guidelines for at least two reasons:

1. The first is that it should not be assumed that the person with AGIO has a mental illness that is likely to blur his or her judgment about medical treatment. It follows that the presumption should always be that the applicant is competent to make judgment about his or her condition and related treatments, unless evidence of the contrary is found.
2. The second is that, if part of the individual's suffering relates to unrealistic stereotypes, treatment for AGIO should include interventions in the family and, in the longer term, in the society at large, with an aim to inform the public at large of the normalcy of gender ambiguity. Any future guidelines should devote a section to the importance of social education on the matter and insist on the importance of informing the general public about the existence of gender ambiguities as a normal part of human diversity.

6. Available Interventions

Broadly speaking, intervention for AGIO includes three stages (Royal College of Psychiatrists, 1998, p. 5).

1. *Fully reversible interventions*: these include hypothalamic blockers, which are meant to suppress oestrogen in girls and testosterone in boys. These are also called simply 'blockers'.
2. *Partly reversible interventions*: these include masculinising and feminising hormones. These are meant to promote the development of secondary sexual characteristics in line with the core gender identity experienced by the young person.
These are called 'partly reversible' interventions because some secondary characteristics are very difficult to reverse (for example, voice change and beard growth cannot be changed; breast development can be only removed with surgery).
3. *Irreversible interventions*: these refer to surgical procedures.

7. Current Guidelines

7.1. Current Guidelines for Fully Reversible Interventions

The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders states that:

Adolescents [note: not children below this age] may be eligible for puberty-delaying hormones as soon as pubertal changes have begun. In order for the adolescent and his or her

parents to make an informed decision about pubertal delay, it is recommended that the adolescent experience the onset of puberty in his or her biologic sex [. . .]. In order to provide puberty delaying hormones to an adolescent, the following criteria must be met:

1. *Through childhood the adolescent has demonstrated an intense pattern of cross-sex and cross-gender identity and aversion to expected gender role behaviors;*
2. Sex and gender discomfort has significantly increased with the onset of puberty
3. *The family consents and participates in the therapy* (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, 2001, p. 10) (my emphases).

The Royal College of Psychiatrists recommends that adolescents have experience of themselves in the post-pubertal state of their biological sex (Royal College of Psychiatrists, 1998, p. 5).

However, where, for clinical reasons, earlier intervention is thought to be in the patient's interest, this must be managed within a specialist service with paediatric endocrinological advice and more than one psychiatric opinion (Royal College of Psychiatrists, 1998, p. 5)

The British Society for Paediatric Endocrinology and Diabetes states, categorically, that "an adolescent should be left to experience his/her natural hormone environment uninterrupted until:

- a. Development of secondary sexual characteristics is complete
- b. Final height has been achieved
- c. Peak bone mass has been accrued (ideally)" (BSPED, p. 2)

The extracts from the guidelines above show a degree of incongruence. This is the sign of lack of consensus among therapists as to the best course of action and to the risks and benefits associated with early intervention.

7.2. Current Guidelines for Partially Reversible Interventions

The Harry Benjamin Guidelines states that masculinising and feminising hormones (partially reversible intervention) may be administered

"as early as age 16, preferably with parental consent" (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, 2001, p. 10).

But they also state that

"[h]ormonal treatment should be provided only to those who are legally able to provide informed consent. This includes persons who have been declared by a court to be emancipated minors [. . .]. For adolescents, informed consent needs to include the minor patient's assent and the written informed consent of a parent or legal guardian" (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, 2001, p. 17).

There seems to be a clear contradiction between the two statements within the same guidelines. The first statement “preferably with parental consent” implies that family consent (or the guardian’s consent) is not strictly required; the second implies that it is.

We shall see that such demand for parental consent represents a departure from English legislation on consent by competent minors. It is also inconsistent with respect for ethical principles of respect for people’s autonomy and promotion of their best interests, which English law has incorporated (Mason *et al.*, 2006, chapter 1). Whereas it could be considered good practice to *try to obtain* parental consent and to involve the family in the treatment of the minor with AGIO wherever possible, the minor’s best interests should be protected when it is clear that the parents fail to protect the best interests of their child.

7.3. Current Guidelines for Irreversible Interventions:

The Harry Benjamin Guidelines state that

“[a]ny surgical intervention should not be carried out prior to adulthood, or prior to a real-life experience of at least two years in the gender role of the sex with which the adolescent identifies. The criterion of 18 should be seen as an eligibility criterion and not an indication in itself for active intervention” (The Harry Benjamin International Gender Dysphoria Association’s Standards of Care for Gender Identity Disorders, 2001, p.11).

The Royal College of Psychiatrists (UK) also states that irreversible interventions “should not be carried out prior to adulthood at age 18” (Royal College of Psychiatrists, 1998, p. 6).

8. Ethical Issues

The main ethical issues involved in the treatment and care of children and adolescents with AGIO are:

1. Whether people and in particular children and adolescents can give valid informed consent to treatment for AGIO;
2. Whether it is ethical to provide treatment with an uncertain outcome to patients who request it, in particular children and adolescents.

These two general issues present several facets, which I will address in the following sections.

One fundamental principle at the heart of many claims of respect for therapeutic decisions is the principle of respect for people’s autonomy. It is because we believe that people’s autonomy should be respected, that many times we fight to defend people’s right to make medical decisions. English law enshrines the ethical principle of respect for individual autonomy.

9. Principle of Respect for Autonomy—Ethics and Law

The principle of respect for autonomy is one of the pillars of democratic societies. Its importance is recognised in virtually all treaties and conventions of human rights and fundamental freedoms (General Assembly of the United Nations, Universal Declaration of Human Rights, 10 December 1948; Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms, Rome 4 November 1950; Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4 April 1997) (Giordano, 2000).

The principle of respect for autonomy holds that each individual has the freedom to shape his or her life according to his or her own personal values and preferences, as far as his or her freedom does not harm others, even if the vast majority of people consider his or her values and preferences irrational or mistaken.

The principle of respect for autonomy has been incorporated in English healthcare law and in other jurisdictions across the world. One of the ways through which this principle is implemented in healthcare is through informed consent. *Prima facie*, patients should give valid informed consent to medical procedures and that consent should be respected.

In the case of AGIO, one of the main ethical issues is whether it is possible to provide valid informed consent to treatment.

10. Autonomy and Informed Consent in Agio

In general, in order to be valid, consent should be:

- a. fully informed
- b. competently given
- c. uncoerced

The most acute problems arise in connection with points a) and b), as not one case of a child coerced by someone else to require treatment for AGIO has ever been reported. With regard to a), full information, there is no such a thing as 'full information'. No doctor could deliver 'full information' to a patient in the sense that absolutely everything relevant to the decision has been raised and considered. Even the notion of information *that is material to the decision* is vague and context dependent. We cannot realistically expect that consent can ever be fully informed. Clearly the knowledge of the risks and benefits of proposed treatment and alternatives is material to the decision. This, as we are now going to see, may pose a challenge in the case of AGIO. Risks and benefits of available treatments

are, in fact, not fully established. The following sections will report risks and benefits of the three stage treatments for AGIO. I will argue that this does not impinge upon ethicality of treatment and that patients, including children, can nonetheless give valid informed consent to treatment.

10.1. Clinical Benefits and Risks of treatments for AGIO

Puberty delaying hormones. These have the following benefits:

- a. The main benefit of early physical treatment is arrest of pubertal development, and, consequently, arrest of the suffering of the patient (Cohen-Kettenis *et al.*, 2003, p. 171).
- b. Arresting the progress of puberty gives adolescents more time in which to achieve greater certainty about their innate gender identity.
- c. The administration of blockers will prevent the development of secondary sexual characteristics of the undesired sex. In turn, future treatment would be less invasive and painful (for example, breast removal in female-to-male patients and painful and expensive treatment for facial hair in male-to-female patients will be prevented; the voice will not deepen, and nose jaw and crico-cartilage (Adam's apple) will be less developed) (Cohen-Kettenis *et al.*, 2003, p. 171).
- d. Successful adaptation is associated with early start of physical treatment (Cohen-Kettenis *et al.*, 2003, p. 171).

The risks are currently under scrutiny. The British Society of Paediatric Endocrinology and Diabetes, composed by the UK team involved in the treatment of gender dysphoric young people, believes that interrupting the development of secondary sexual characteristics may disrupt the fluidity that characterises puberty, and arrest the natural changes that may occur in this period (BSPED). In other words, *in theory*, blockers may inhibit the spontaneous formation of a consistent gender identity, which sometimes develops through the 'crisis of gender'.

Although the concern is serious and should always be taken into consideration when administering therapy in early puberty, it is also known, as stated above, that the vast majority of AGIO adolescents (unlike pre-pubertal children) almost invariably become AGIO adults (Cohen-Kettenis *et al.*, 2003, p.172), even where hormone-blockers have not been administered. This means that there is a clear expected benefit in the vast majority of cases of adolescents requiring treatment.

Other risks currently under scrutiny concern bone formation. The BSPED believes that "to interfere with normal pubertal development may result in [...] failure to achieve adequate peak bone mass, body segment disproportion [...]" (BSPED, p. 1).

This worry is however speculative and is not confirmed by existing studies on the skeleton. Peggy T. Cohen-Kettenis and Henriëtte Delemarre-van de Waal at the Departments of Medical Psychology and Pediatrics VU medical center, Amsterdam, The Netherlands are studying these effects. Their follow up includes assessment of bone density and body composition—yearly; skeletal age—yearly, endocrine and metabolic parameters—every 6 months—and anthropometry (overall height, weight, sitting height, skin folds, waist and hips)—every three months. Their studies show that it is possible successfully to suppress endogenous puberty with GnRH analogue. Through administration of this analogue and, later, cross-sex hormones, it is possible to manipulate overall height. There is no evidence that long term treatment with GnRH analogue results in bone mass loss or disproportionate sitting height, and long term treatment with GnRH analogues in adolescents has shown no side effects related to metabolic factors (Cohen-Kettenis *et al.*, 2005).

Among the risks associated with use of blockers in early puberty, we should include that they will prevent the storage of sperm (for male-to-female children) and, eventually, of ova (for female-to-male children), for future reproductive purposes. However, spermatogenesis will be restored if treatment is interrupted. The child can therefore postpone decisions regarding reproduction to a later date. He can stop treatment long enough for spermatogenesis to occur, if he wishes to collect and store sperm for reproductive purposes. Collection of ova (for female-to-male children) for future reproductive purposes is less problematic, as the treatment has little impact on the already formed ova. They may be collected and stored at the time of oophorectomy (De Sutter, 2005). In addition, the genital tissue available for the later creation of a vagina in trans girls, will be less than would otherwise have been available. From a medical point of view, this problem could be resolved with appropriate surgical intervention.

Current evidence on risks and benefits of blockers in children and adolescents does not seem to justify the strong resistance of the UK team to administer such treatment, especially considering the known risks of refusal of treatment. Current evidence seems to justify the approach taken by the Dutch team, whose professionals are willing to treat children after pubertal hormones have begun to have an effect, but before the adverse sex characteristics have developed to any noticeable degree (this stage is known as Tanner Stage 2). In some children this could be from the age of 10. The Dutch team begins treatment only after careful assessment of the individual case and provided that the patient accepts a long term follow up (personal communication by the Dutch team, May 2005). Notably, Peter Lee, a clinician working in the field since the 60s, currently at the Penn State College of Medicine, Hershey, Pennsylvania, USA, has argued for a similar way of approaching children and adolescents with AGIO.

"We believe suppression of pubertal sexual characteristics is warranted when there is evidence of pubertal onset. Suppression of pubertal sex steroid production—he and Christopher Houk write—and thus secondary sexual characteristics can be effectively and safely accomplished using gonadotropin-releasing hormone analogues (GnRHa)—an intervention that is both temporary and reversible".

They also describe how treatment protocol includes bone density control and cross-sex hormones administration (Lee *et al.*, 2006).

However, from an ethical point of view, some may question the validity of consent, where risks and benefits are not fully established (see below).

Cross-sex hormones. This treatment is almost universally withheld until at least the age of 16. Treatment protocols require that side effects be carefully monitored. Cross-sex hormones have the following benefits:

- a. They initiate the development of the secondary sex characteristics of the desired gender. Thus, they make it possible for the person to match the body, at least to some degree, with the innate gender identity;
- b. They make it easier for the person to have a real life experience;
- c. They allow the person to explore what it feels like to be the other gender, thus making it possible to make a better informed choice about irreversible interventions

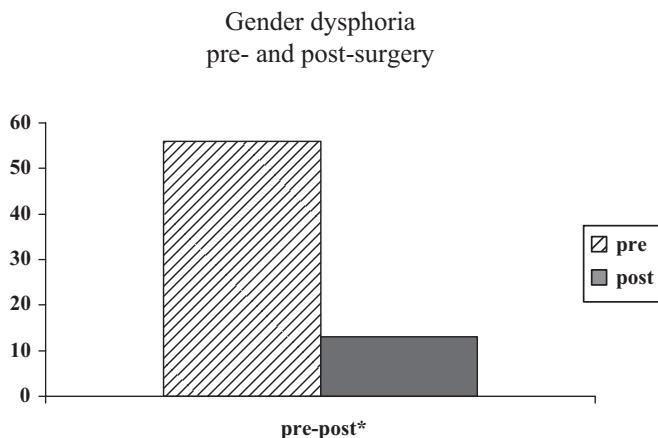
Risks are mainly cardiovascular. Cross-sex hormones seem to increase the likelihood of occurrence of serious/fatal cardiovascular diseases in patients already at risk (smokers, obese patients, patients with heart diseases, hypertension, clotting abnormalities, or some endocrine abnormalities). Most of the risk factors that have just been listed mainly concern adults and generally do not apply to children and adolescents.

Other risks are the following: in males, estrogens and progestins may also cause infertility, weight gain, emotional lability, liver disease, gallstone formation, somnolence and diabetes mellitus. In females, testosterone may cause infertility, acne, emotional lability, increased sexual desire and hepatic dysfunction and even malignant liver tumours (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, 2001, p. 15).

One final important risk associated with cross-sex hormones is that the treatment is only partially reversible. If a patient decided to interrupt treatment, effects such as voice change and beard growth cannot be changed, although possibly ameliorated, and breast development in males through administration of estrogens and progestins can be only removed with surgery.

Surgery. Surgery may represent the final stage of treatment for AGIO, although continuing hormone intervention is an additional lifelong treatment. Surgery is performed, extremely rarely, if at all, for those young people under the age of 18.

With regard to the benefits of surgery, they are evident. The patient has finally obtained a body that is in line with innate gender identity. According to a study, body satisfaction significantly increases in the vast majority of cases (see below).



Clinical management of adolescents with gender dysphoria

Peggy T. Cohen-Kettenis, Henriëtte Delemarre-van de Waal Departments of Medical Psychology and Pediatrics, VU medical center, Amsterdam, The Netherlands (Cohen-Kettenis *et al.*, 2005)

Risks of surgery include normal risks associated with all surgery. Additional risks concern body dissatisfaction. A small percentage of people who undertake surgery are not satisfied with the transition. Peggy T. Cohen-Kettenis and Friedemann Pfäfflin report the case of the first male-to-female sex reassignment surgery (Berlin 1920). After the patient was surgically castrated and an ovary was implanted, the patient

“lost his transvestic and transsexual urges, returned to a male lifestyle, had the surgery redone, lived and cohabitated with a woman . . .” (Cohen-Kettenis *et al.*, 2003)¹.

Clearly, reversing surgery involves expensive and invasive procedures, which in some cases can only be partially successful (GIRES, 2005).

¹⁾ It would be interesting to explore the reasons for dissatisfaction. We discussed, above, the bi-polarity ‘female-male’ which is incorporated in our way of thinking about gender identity. It is possible that dissatisfaction with transition is also linked to this rigid bi-polarity. The identity of some people may be an ambiguous one, a ‘chiaroscuro’. Some people may be dissatisfied with a rigid gender identity, whatever that is. It therefore seems that, beyond improvement of medical services, treating AGIO involves re-thinking about gender identity, myths, stereotypes and expectations that we have around gender identity, in a way which is similar to the way we have re-thought sexual preferences (hence homosexuality and bisexuality are no longer regarded either as perversions or as mental illnesses but as a part of who we are)

Although there are risks involved in administering treatment for AGIO, there are also risks involved *in refusing* to administer such treatment to children and adolescents.

10.2. Risks involved in refusing to treat children and adolescents

- a. First, delaying treatment means in many cases delaying release from suffering;
- b. Second, it means allowing the development of secondary sexual characteristics, which makes surgery more invasive at a later stage;
- c. Third, there are more general risks, summarised by Bran Fenner and Rickke Mananzala (FIERCE) and by Z. Arkles and Dean Spade (Sylvia Rivera Law Project).

For these youth [children and adolescents with AGIO], being turned away for hormone treatment at clinics has a number of effects. First, it further alienates them from medical providers, about whom they may already feel distrust or fear. Because of this increased distrust, many may not return for primary care, HIV testing, STD treatment and other essential care [. . .] Besides creating a disincentive for other medical care and alienating youth from medical services, these age-based denials also create a necessity for youth who feel that hormone therapy is essential to their survival to seek this care out elsewhere. For many, this care is the only way to express their gender fully so that they can seek employment, attend school, and deal with every day interactions in their new gender. Without hormones, many have a difficult time being perceived by others correctly, opening them up to consistent harassment and violence. For many young people [. . .] taking hormones feels like a life or death need, and they will do whatever is necessary to get this treatment. Many, when rejected at a clinic based on age, buy their hormones from friends or on the street, injecting without medical supervision at dosages that may not be appropriate and without monitoring by medical professionals. This opens them up to high risk for HIV, hepatitis, and other serious health concerns. Additionally, many youth have difficulty raising money to buy these hormones illegally because they do not have parental support for their transition and face severe job discrimination as young transgender applicants. For many, criminalized behaviour such as prostitution is the only way to raise the money. Doing this work makes them vulnerable to violence, trauma, HIV, and STD infection, and entanglement in the juvenile justice system [. . .] Once a young person enters the juvenile justice system, the stigma of delinquency usually follows them throughout life and they often cycle into the adult criminal justice system upon maturity (Fenner et al., 2005)

Untreated children and adolescents with AGIO are at high risk of suicide.

10.3. 'Fernanda is a Doll of Silk': How will I Feel after Transition?

The previous sections have shown that treatment for AGIO, especially in childhood and adolescents, presents risks and benefits which are currently under scrutiny.

Even if the effects of various hormonal treatments were clearer, there would always be a degree of unpredictability inherent in gender transition. However dissatisfied an individual may be in his/her gender, s/he cannot be absolutely certain of how s/he will feel in a different gender.

This problem, which is existential, and not merely clinical, applies to adults as well as to minors.

Fernanda Farias (a woman from Brazil) narrates her story in her biography, written with Maurizio Janelli (Farias *et al.*, 1994). After transition, she feels that her female identity is not a complete one. There is a degree of artificiality in her femininity, which she experiences as partly frustrating. She felt 'different' as a man; and now she feels 'different' as a woman. In order for her body to look like her, Fernanda had to suppress a part of the self (Fernando) but what she becomes is not exactly a woman, not a woman like everyone else. Her femininity is incomplete. Her experience has been caught in the verses: "Fernandino died in my womb; Fernanda is a *doll of silk*" (De Andre' *et al.*, 1996). Even in a woman who has 'successfully' completed transition, the expectations related to gender transitions have not been fulfilled entirely.

Fernanda's experience illustrates at least two things: one is that expectations about gender identity, either among 'normal' people or among those with AGIO, may be unrealistic. To be *one or the other* is not everyone's reality. For some, ambiguity is the reality. But whereas it is difficult to accept the incongruence with phenotype, ambiguity—that is, living in a chiaroscuro, being both ways, both woman and man, meets with much harder social and psychological resistance. The second thing that Fernanda's experience illustrates is that it is not always possible for individuals to foresee how they will feel once they have changed gender.

This may all be thought to impinge upon the validity of informed consent and on the ethicality of treatment, especially in children and adolescents.

10.4. Is it Possible to Give Valid Consent when Risks and Benefits are Unclear?
It may be believed that since the risks and benefits of gender transition cannot be fully established in advance (here including risk of incomplete satisfaction), it is not possible to give valid informed consent to gender transition. Children and adolescents might be believed to have greater difficulty in foreseeing how they will feel in the future, due to the scarcer capacity for of their long term judgment and scarcer knowledge of the self. It may be also believed that, since consent to treatment whose effects are unknown cannot be valid, it would be unethical to offer such treatments, especially to children and adolescents, towards whom we have greater responsibility.

The idea that partial unpredictability invalidates consent is mistaken. Despite the partial unpredictability of the outcome of treatment for AGIO, it is possible to give valid informed consent. Once informed of the unknown effects of desired treatment, a person can make an informed choice as to whether or not to commence treatment. In the balance, the person will ponder the unknown results of treatment with the potential benefits, and will set them against the all too real and known psychological and physical effects of non-treatment. If it were impossible

to give valid consent to treatment whose side-effects are unclear, it would follow that consent to participation in medical research would be impossible, and that medical research involving human patients is necessarily unethical.²

The belief that offering treatment for AGIO is, or risks being, unethical due to its unpredictability is also mistaken. Indeed, the complete outcome of many medical treatments is unknown before they commence. This does not preclude the patient giving informed consent. What is important is that patients are put in the position to make an informed choice. Patients need to receive honest information about known and unknown risks and benefits of the treatment. Allowing them to choose on the basis of honest information is to respect their values, their autonomy, and the way they wish to shape their own lives. Valid informed consent can be obtained even if risks and benefits cannot be fully established.

It is true that children and adolescents might have scarcer self-knowledge and scarcer capacity to predict their long term preferences. However, it cannot be excluded that they are capable of a competent judgement upon the matter, and therefore their request has to be evaluated on an individual basis, without assumption that their consent cannot be valid or that treatment cannot be ethical.

The other element of informed consent that may raise particular problems in the case of AGIO in minors is competence.

11. *Minors and Competence*

In Anglo-Saxon jurisdictions a person is deemed competent if s/he understands in broad terms the nature of his/her condition, purposes of proposed treatment and alternatives, and can balance risks and benefits of proposed treatment and alternatives. Competence "does not depend on the age of the child, but on subjective features of the child in respect to the particular treatment proposed" (Jones, 2006, p. 129).

Section 8 of The Family Law Reform Act 1969 states that a minor who has attained the age of 16 years can give valid consent to any surgical, medical or dental treatment. Where a minor has by virtue of section 8 given effective consent to any treatment, it shall not be necessary to obtain consent from his/her parent/s or guardian (Brazier, 1992, pp. 361–71).

²⁾ In fact, I have suggested that UK clinicians working in the field should openly propose a therapeutic research protocol, rather than a therapeutic protocol (personal communication to the team, May 2005). Pretending to offer treatment seems to be incongruent with reality, given the unpredictability of results and scarce knowledge of AGIO. It is accepted that the Dutch team operates a similar research on children and adolescents (Russel Viner, communication to the team, April 2006). In the UK, there seems to be strong resistance to the idea of openly stating that treatment of children and adolescents with AGIO involves research.

In this section 'surgical, medical or dental treatment' includes any procedure undertaken for the purposes of diagnosis, and this section applies to any procedure (including, in particular, the administration of an anaesthetic) which is ancillary to any treatment as it applies to that treatment.

Gillick v West Norfolk and Wisbech Area Health Authority ([1986] A.C. 112) established that a child *under 16* is competent and can give an effective consent to medical treatment providing that she had reached –

"... sufficient understanding and intelligence to be capable of making up his own mind in the matter requiring decision" ([1985] 3 All ER 402 at 409 e-h per Lord Fraser and at 422 g-j per Lord Scarman; See also *R v. D* (1984) 2 A11 ER 449)

Although the implications of Gillick in terms of children's right to autonomy are discussed (Freeman, 2006), the 'Gillick competence' is now regarded as the landmark of adolescent autonomy in health care (Eekelaar, 1986, p.1).

From this brief outline it results that there is no ethico-legal ground for presuming that a child with atypical gender development cannot be competent to make a judgment upon his or her own condition and upon commencing treatment with blockers at an early stage (for more detailed discussion of competence and the courts in gender re-assignment cases see Jones, 2006).

In the light of all this, I will now propose a way forward in the construction of new guidelines. The new guidelines should ensure that a number of ethical principles are respected.

12. Ethical Principles at The Basis of New Guidelines

12.1. Consistency

One of the most important ethical principles in general and in particular in health care settings is that of consistency. The guidelines that apply to children with AGIO must be consistent with legal and ethical principles that apply to children who suffer from other conditions, unless a relevant difference justifies the difference.

Current guidelines seem not to fully respect this principle. For example, it is unclear why a competent 16 year old person cannot commence treatment for AGIO without parental consent, whereas the Family Law Reform Act 1969 recognises that he or she has such a right. Note that the Act refers also to diagnostic purposes, as we have seen above. Whereas partially reversible and irreversible interventions for AGIO are not diagnostic, but clearly therapeutic measures, the reversible intervention, the administration of blockers, could also be described as diagnostic. It is also unclear why there is an *a priori* veto on surgery before the age of 18 in the case of AGIO.

Current guidelines also seem inconsistent with Gillick. If the child with AGIO is 'Gillick competent', it seems that, by consistency, at least *prima facie*, the same

treatment accorded to Gillick should be granted to minors who request treatment for AGIO.

It could be argued that Gillick is different from AGIO in at least four important ways:

- First, Gillick was about contraceptive advice and administration of contraceptive pill. Contraceptive pill has much less invasive effects on the child than blockers and hormones utilised in treatment for AGIO;
- Second, contraception is fully reversible (though blockers administered at the earliest stage of therapy also are);
- Third, the side-effects of contraception are much clearer than side-effects of treatment for AGIO;
- Fourth, gender transition has an obvious impact on family dynamics, and it is therefore crucial that family participates.

These differences may of course justify different approach to AGIO, as compared to administration of oral contraceptives. If we use special caution because of special circumstances surrounding treatment for AGIO, these circumstances should be clearly stated in the new guidelines. If the guidelines, at least apparently, depart from legal principles accepted in English law and from ethical principles that are incorporated in legislation, the reasons for such departure need to be explained. People need to be offered an explanation as to why they are being treated differently, otherwise they will perceive difference in treatment as unjust discrimination; they may see themselves as being wronged. In order to respect the principle of consistency, the new guidelines will have to either eliminate any existing incongruence, or justify why children and adolescents with AGIO should be treated differently from other children. One final note. Special caution may and should require an individual assessment of each applicant. However, it is desirable that procedures of assessment attempt to minimise the involvement of the courts. The description of what Alex went through, which is confidential and is contained in reserved files, is heart breaking (by Court Order the File Number and names of Counsel and Solicitors have all been suppressed. The case is *Re Alex [2004] FamCA 297*). We should hope that children already in distress are spared the further distress associated with long and complex court cases.

12.2. Equality and Ageism

One of the fundamental ethical principles accepted worldwide and reiterated in virtually all declarations of human rights is equality. The principle of equality is widely debated in philosophy and ethics, but in essence it means that people should be granted similar treatment and respect, unless a relevant difference among

them justifies difference in treatment. It is clear that treatments will vary according to the people being treated. However, discrimination needs to be based on relevant differences among individuals. Declarations on human rights assist us in identifying which differences among individuals are not relevant (Besson, 2005).

The Charter of Fundamental Rights of the European Union for example states what is unethical:

Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation (Art.21, Non-discrimination) (Available at http://www.europarl.eu.int/charter/default_en.htm.)

Similar statements occur in virtually all other declarations and conventions, for example, in the Convention for the Protection of Human Rights and Fundamental Freedoms as amended by Protocol n. 11, 4 November 1950, art.14, Prohibition of discrimination (Available at www.echr.coe.int/Convention/webConvenENG.pdf); in the Convention for the Rights of the Child (2 September 1990), Preamble (Available at <http://www.unhchr.ch/html/menu3/b/k2crc.htm>); in the European Social Charter (Revised) (3 May 1996), Part IV, Art.E. (Available at <http://conventions.coe.int/Treaty/EN/Treaties/Html/163.htm>)

In the field of health care, age is regarded as one of the arbitrary features that do not justify difference in treatment. Competence and capacity to benefit from treatment, among others, are relevant and do justify difference in treatment. Competence and capacity to benefit from treatment often are a function of age, but this is not always the case. In fact, as Gillick shows, a minor can be competent to make a particular decision. His or her age is not the determinant element: the determinant element is competence, and competence, which often matures with age, sometimes is manifested very early in life.

The World Health Organisation (WHO) and the United Nations (UN) have condemned any form of “ageism”, including ageism in health care provision (*Brasilia Declaration on Ageing*, WHO, 1–3 July 1996, Available at <http://www.oneworld.org/helpage/info/brasilia.html>) (UN International Year of Older Persons, 1999, Available at <http://www.un.org/esa/socdev/iyop/>). Age-based discrimination is deemed to violate the principle of equality. Normally, these rules are meant to protect the older person, but they can and should also be applied to the child. Refusing to treat simply on the basis of age is a form of ageism (unjust discrimination based on age). Healthcare professionals need to provide valid reasons to refuse medical treatment: they need to show that the treatment is not in the best interests of the child, or the child is incompetent to make such a decision at this stage of his/her life, and the risks of the treatment outweigh its expected benefits. Appeal to age alone is ethically unsound and incongruent with English law.

The existing guidelines set up age limits for access to treatment, they risk violating both the principle of consistency and the principle of equality as non-discrimination. Setting up limits to access to medical services based on age is ageist.

Healthcare professionals could argue that, given the degree of unpredictability in the outcome of such treatment, it is irresponsible to give treatment to children. However, those who believe that administering treatment with a degree of unknown risk is unethical should also refuse to administer that treatment to adults. If it is irresponsible and/or unethical to provide treatment whose risks and benefits cannot be fully established in advance, then it is irresponsible and unethical regardless of the age of the applicant. If instead, as it is reasonable to believe, the healthcare professional will be willing to provide this treatment, when there is reason to believe that the benefits outweigh the risks, that the risks of not providing treatment are higher than those involved in treatment, that the person is competent to choose to take those unknown risks, which he or she sets against the real suffering of his or her existing condition, then those reasons should apply to both adults and children. If the same principles do not govern treatment of adults and children, it should be explained why this is so, or else the health care profession risks making an act of strong paternalism that is ethically unjustifiable and legally questionable.

This does not mean that treatment of AGIO must be offered, that doctors have a moral and legal obligation to treat people who request it. It means that the rationale for withholding treatment must be made out on other grounds, and not on the basis of the age of the applicant.

Current guidelines, which insist on age limits for access to treatment, risk being incongruent both with English legislation and with fundamental ethical principles. New guidelines will have to take into account both consistency and equality understood as non-discrimination.

12.3. Acts and Omissions

Doctors do not have an obligation to treat just because a patient wants treatment, even if the request is made competently. They are entitled not to treat, based on their clinical judgement or on their moral values. They are for example entitled, on the basis of conscientious objection, to refuse to perform abortions (although this entitlement is not absolute; when risks for health are serious and imminent a doctor who refuses to perform abortion could be charged for negligence). However, in pondering the ethical plausibility of treatment, health care professionals—and hence the guidelines that should direct their conduct—should not regard omitting to treat as an ethically neutral option.

Some may believe that we are only responsible for our actions, and that if we do not act, we are morally (or legally) safe. However, it is not clear that, both from a legal and an ethical point of view, failing to act is always a safe option. In

the Gillick case, for example, Lord Fraser argued that the doctor should meet the patient's request, provided that ". . . (1) that the girl . . . will understand his advice; (2) that he cannot persuade her to inform her parents . . . ; (3) that she is very likely to begin or continue having sexual intercourse with or without contraceptive treatment; (4) that unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer; (5) that her best interests require him to give her contraceptive advice or treatment or both without the parental consent" (emphases are mine). ([1985] 3 All ER 402 at 409 e-h per Lord Fraser). The final decision in Gillick was made also in view of the *consequences that were likely to occur if contraceptive advice and treatment were not given*: continuation of sexual intercourses without contraceptive; likely physical and/or mental suffering. This implies that doctors can be held responsible for what happens to patients if they fail to administer requested treatment.

In the case of AGIO, practitioners may be reluctant to take responsibility for the act of starting treatment. Because side-effects of treatment are under scrutiny, doctors may feel that their duty not to harm is best served by not taking the risks that may be associated with therapy. Given that they are dealing with children, they may feel a very strong responsibility not to subject them to any risk that they cannot foresee and therefore control, and may thus be inclined to postpone treatment at a later stage, in good faith that they are doing no harm and therefore acting morally. Such a psychological reaction on the part of clinicians is understandable, but is not fully grounded, from an ethical point of view. There is also, in fact, a responsibility for omitting to treat. Omitting to treat at the right age may have a number of adverse consequences, as we have seen in section 10. Omitting treatment at pre-pubertal age means allowing a series of physical changes to occur, when those changes are unwanted and are highly likely to have gravely adverse consequences when the adolescent continues to experience transsexualism. This is a harm that can be avoided by blocking pubertal changes and then administering cross-sex hormones at a later stage.

The issue of whether we are *equally* responsible for our omissions as well as for our acts, and of *how responsible* we are for our omissions, is widely debated in ethics.

If we are *equally* responsible for our omissions, this means that doctors who refuse to treat are responsible for what is likely to happen to the untreated child or adolescent in the same way that they are responsible for what is likely to happen if they provide treatment. This seems to be a too stringent responsibility. It may be argued that doctors cannot share responsibility for what potential patients choose to do, once they are refused treatment. For example, practitioners cannot be held accountable for people obtaining hormones in the illegal market once they refuse to provide hormones to them. Likewise a doctor who fails to treat cannot be charged with murder, if the applicant commits suicide.

However, although no-one can be held responsible for other people's actions, we are all responsible for what *we* omit to do (rather than for what others do). Inaction is not necessarily a 'morally safe place' to be in. When we know that if we fail to do something, the consequences for our omissions are serious and potentially fatal for others, we have some moral responsibility for those consequences. The extent to which we are responsible for our omission can be debated, but it is mistaken to assume that we are in no way responsible for the foreseeable consequences of our inaction, whereas we are responsible for the foreseeable consequences of our actions.

Future guidelines should incorporate the known risks for omitting treatment in minors, and should clarify that both in law and ethics it is accepted that doctors are to some (variable) extent responsible for omissions, as well as for actions, in particular when it is known that not being treated can cause great harm to some children and adolescents. This clearly would imply that guidelines revise the age criteria and invite health care professionals to make a case-by-case evaluation of the clinical and ethical appropriateness of early treatment, considering the applicant's competence, best interests, and risks involved in not commencing treatment when requested by the applicant.

Final Remarks

This paper has explained what AGIO is, how it manifests itself, what are the available interventions and the nature of the potential side-effects of various interventions. Some issues, such as the impact of AGIO and treatment for AGIO on family dynamics, have been neglected for reasons of space.

Different countries adopt different policies with regard to treatment for AGIO in children and adolescents. In the UK, there has been considerable resistance to the idea of revising current guidelines. Yet, I have shown that these guidelines present some problems and need to be revised:

1. Current practice in the UK (2006) is, to some extent, inconsistent with the provisions contained in the Family Law Reform Act 1969 and with relevant case law. The incongruence refers, in particular, to the involvement of the family and to respect for the minor's competent choices.
2. Setting up an age limit before which treatment cannot commence is a form of ageism, and contrary to the present legal concept of *Gillick* competence.
3. There seems to be an underlying assumption, in current UK guidelines, that doctors are not responsible for omissions, but only for actions. This assumption is mistaken, and even UK case law has recognised that doctors should take consequences of refusal to treat into consideration.
4. Doctors are required to do no harm. Yet, requiring a series of physical changes to occur before treatment, when those changes are unwanted and are highly

likely to have gravely adverse consequences when the adolescent continues to experience transsexualism, is harm that can be avoided by blocking pubertal changes and then administering cross-sex hormones at a later stage.

5. Existing evidence on known and unknown risks and benefits does not seem to justify the veto accepted by UK professionals to administer blockers to children.

From an ethico-legal point of view, it seems that future guidelines should be framed around the following points:

1. Children's requests for treatment should be fulfilled, provided that the children are competent and that treatment is in their best interests. A more restrictive approach can only be justified if the reasons for departure from accepted ethical and legal principles are clearly explained;
2. Age-related criteria of access to treatment should be eliminated. Focus should be on competence and on best interests of the child/adolescent, in coherence with legal and ethical principles accepted in the UK;
3. If family participation is made essential to treatment of minors with AGIO, it should be explained why this is so;
4. Guidelines should emphasise ethical principles, such as respect for the autonomy of the child. Where the exercise of autonomy does not take precedence, in any particular case, an explanation for this departure from the ethical principle must be fully documented;
5. Guidelines should incorporate respect for consistency and equality, and avoid any form of unjustified discrimination;
6. Guidelines should stress that in law and ethics it is accepted that healthcare professionals are, at least to some extent, responsible for omissions, as well as for actions. Although this does not imply that they must treat, that they have an obligation to treat, nonetheless, healthcare professionals should be made aware that, both legally and ethically, refusal to administer treatment is not always a safe option and may be open to ethico-legal challenge.

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